Children and Family Series

Beyond the Limits:

Mothers Caring for Children with Disabilities

L'Institut Roeher Institute

ROEHER INSTITUTE

104-06053/

BEYOND THE LIMITS:

MOTHERS CARING FOR CHILDREN WITH DISABILITIES

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Canadian Cataloguing in Publication Data

Main entry under title:
Beyond the limits: mothers caring for children with disabilities

Includes bibliographical references and index.
ISBN 1-896989-53-5

1. Parents of handicapped children - Canada. 2. Handicapped children - Home care - Canada . I. Roeher Institute.

HV890.C3B49 2000 362.4'083'0971 C00-932512-3

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The Roeher Institute gratefully acknowledges the generous financial assistance of the Canadian Association for Community Living who collaborated with The Institute on this project with funding from Social Partnerships at Human Resources Development Canada. The Women's Health Bureau at Health Canada also provided generous support in making this study and publication possible. The findings and opinions expressed in this report are solely the responsibility of The Roeher Institute.

The recommended citation for this publication is:
Roeher Institute, *Beyond the Limits: Mothers caring for children with disabilities,*
North York, Ont.: L'Institut Roeher Institute, 2000.

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About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

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FOREWORD

A lack of recognition of the realities of families caring for children with disabilities marks the Canadian psyche. We are not a unique society in that regard. Collectively, we seem unable to witness how children with disabilities, their mothers and fathers and sisters and brothers are putting their families together. We seem unable as a society to acknowledge and value the sometimes difficult path they travel, and the support they need to do so. Mothers interviewed for this study generously offered a glimpse into their daily lives. They spoke of the struggles and joys of families who have a child with a disability. They drew a picture wrought with frustration — not because of a child's particular abilities — but because of support needs that remain unmet; school administrators unwilling to hear their plea to include a child in a regular classroom; recreation staff or child care centres unable to accommodate a child's particular needs; community members unwilling to take the step to see and know their children.

Beyond the Limits seeks to do justice to these mothers' views and hopes, and to the reality of going 'beyond the limits' on a daily basis without the support to do so. This is one of a number of studies in The Roeher Institute's *Child and Family Series* that documents the trends and issues facing families caring for children with disabilities. This particular study provides a unique look at what it takes for parents and mothers, in particular, to create a valued place for their children. It shows how communities, governments and Canadian society too often fail them and disregard their purpose.

What does it mean to acknowledge and become conscious about this growing proportion of families in Canada? First, it means recognizing the work that mothers are doing. The women's movement has made a plea in the past couple of decades — one too often silenced — to acknowledge the dual burden that women carry working both at home and in the paid labour market. The women in this study spoke of what amounts to a 'triple burden of labour' — domestic work, paid work and the 50-60 hours a week on average they spend in providing non-paid disability-related support for their children. The roles played by women interviewed for this study are numerous and time-consuming: educators, advocates, service coordinators, case managers, teacher assistants, teacher educators, part-time nurses, personal assistants, and the list goes on. To date, these roles have remained unvalued, uncompensated and unsupported.

Recognizing and valuing all children and families means owning up to what happens when needed support is continually denied. A society should not continue to ask women to take on a dual burden of labour, much less the triple burden that a growing number of women carry, without understanding the consequences. Women in this study spoke eloquently, humbly and with a considerable amount of pain about what happens to women who walk in their path. Many spoke about the joys of raising their children, but also about the stress, ill-health and personal and family loss that has come with raising their children in a society that seems so unwilling to provide the support they need. Their accounts point to a number of directions for policy reform in the areas of respite services, education, family supports,

income support and the labour market.

It's time to reawaken public consciousness about the place of children with disabilities and their families in Canadian society. To do so will require that accounts, like those given by women for this study, are widely heard and taken seriously. A public willingness and ability to do so may finally be in the offing. As governments at all levels begin to talk about a new 'Social Union' in Canada, and as they move forward on initiatives for a 'National Children's Agenda', we can only hope that a new political culture begins to take hold in Canada — one that acknowledges a deep diversity, that values inclusion, that holds to an enduring sense of social justice and that listens to the stories of families long told, but often unheard. We hope that this study contributes in some way to that effort.

We would like to thank many people who assisted in this study. First, we want to acknowledge the women who gave their time and provided the insight without which this study would not have been possible. The research team at The Institute included Michael Bach, Project Director and Michelle Connel who conducted the interviews, assisted in the literature review, and with Mary Bunch drafted the report in collaboration with the research team. Tom Martin provided statistical analysis, and Cameron Crawford provided advice throughout the project.

The Canadian Association for Community Living generously supported this project, both financially and through assistance in formulating the research and providing feedback on draft reports. We would like, in particular, to acknowledge Connie Lauren-Bowie, who has supported this project and *The Child and Family Series* since its inception. We would also like to thank The Women's Health Bureau at Health Canada who contributed financially to the study.

Michael Bach
Vice President & Director of Research

I. INTRODUCTION

All children are born into families of different sizes and shapes, some with extensive financial and other resources, some stretched by the few resources they have and the demanding responsibilities they take on. The families that children with disabilities are born into are no different. But the face of families caring for members with a disability is changing. Institutional care is less and less an option. Medical technologies enable children with significant disabilities and complex medical needs to survive. Most parents expect that *all* their children will be included in regular schools, local recreation programs, the neighbourhood crowd.

Yet, when the question 'How are families in Canada faring?' is asked, the growing number of families raising children with disabilities are rarely included in the picture. This study seeks to broaden the picture by shedding light on the realities faced by this group of Canadians. The guiding questions of the study are: What are the implications for parents, and especially for mothers who provide day-to-day care for children with disabilities? What roles are mothers playing in order to support their children in the community? How are women and their families coping with increased care requirements for children with disabilities? What are caregivers saying they need from the government, support personnel, family members and community? What has been the community response to the needs of children and their families? In seeking answers to these questions, this study aims to paint a portrait of this often invisible group of families in Canadian society, and to point to directions for policy reform.

The first section of the study briefly outlines the methodology used for the study. Drawing on existing research, the second section examines the current context for families caring for children at home. It explores their needs for support and the socio-economic factors shaping their lives. The issues and trends are explored in more depth in the third section which reports the findings of interviews with 50 mothers in five provinces in Canada, who spoke about the joys and challenges of raising their children at home. The final section points to directions for policy reform that will address the needs that families have in supporting their young children with disabilities at home and in their communities.

II. METHODOLOGY

Literature Review

A review of the current literature on issues facing families that include children with disabilities was conducted. The literature review focused on four areas: service and delivery and support issues affecting the well-being of children and families with respect to respite, education, recreation, child care, health services and transportation; socio-economic factors affecting children and families; current policy issues and literature on community cohesion and capacity building. An extensive bibliography is included at the end of this report.

Telephone Interviews

Organizations that serve a broad spectrum of the population of families of children with disabilities were approached in the following provinces: Saskatchewan, Manitoba, Ontario, Quebec and New Brunswick. Organizations were asked to contact mothers in their communities who were caring for children with disabilities at home to see if they would be interested in participating in this study. An interview instrument was piloted with three interview respondents and then revised.

Follow-up calls were made approximately one week after the organizations received the request package to inquire about the status of the participant list. Many of the organizations contacted responded with names and phone numbers of mothers willing to participate in this project. These mothers were contacted, interview times were arranged and then one-hour interviews were conducted by phone. Mothers caring for children with disabilities at home were interviewed regarding their employment situation, their caregiving responsibilities and the response of their community to themselves and their children. The interviews were conducted in a narrative style, with women asked to provide examples and stories from their experience of caring for and raising their child. Fifty participants representing diverse family types, urban and rural locations, varying levels of income, children of different ages and a variety of disability support needs were interviewed. Interviews were 1.5 to 2 hours in length.

Analysis of Interview Data

As both structured and open-ended questions were used in the interview, the data afforded both quantitative and qualitative analysis. The demographic and health status information collected allowed for a profile of the respondents to be constructed and compared, to some extent, with that of mothers caring for children who do not have disabilities, drawing on the National Population Health Survey, for example. The literature review identified key issues that were explored in the interviews and these provided an initial frame for coding the responses. The framing of these issues and themes was adapated as the analysis proceeded. The open-ended nature of some of the questions, along with the demographic information collected, provided information with which to construct profiles of the respondents. These were written in a manner to communicate some of the lived experiences of mothers caring for children with disabilities. Only those findings from the quantitative analysis that met tests of statistical significance are reported.

III.
FAMILY SUPPORT: THE CURRENT CONTEXT

Children with disabilities are a large and growing population. In 1991 there were an estimated 534,430 children and youth, aged 0–19 years living in Canada who were disabled in some way. More recent estimates indicate that these numbers are even higher. Furthermore, the number of children with disabilities is increasing. Advances in medical technology are increasing the chances for children with severe and medically complex conditions, or injury, to survive into youth and adulthood (Thompson and Gustafson, 1996; Bradley et al., 1995). Children with disabilities are more and more likely to live at home with their families, rather than being institutionalized. Parents, and mothers in particular, are often responsible for providing, coordinating and advocating for care for their children.

Children with disabilities form a diverse group. Disability is associated with a wide range of physical, sensory or cognitive characteristics which pose unique challenges to the support and accommodation capacities of families and communities. Depending on each child's situation, his or her needs for support varies, as do the kinds and extent of barriers to community inclusion experienced by the child and his or her family. Children also differ in terms of gender, ethnicity, culture, personality and interest. They are members of different types of families in various socio-economic, geographic and community contexts. Because of this diversity, support systems must be responsive to a variety of needs and situations, and must be flexible enough to adapt as children's conditions, needs and family situations change.

The Need for Support

Families caring for children with disabilities at home share a number of concerns. The amount of time, cost and energy usually associated with raising children increases dramatically when caring for a child with a disability. Parents often need to take on the responsibilities of nurse, service coordinator, case manager, advocate, trainer and educator (Kirk, 1998; Petr et al., 1995; Haverstock, 1992). Such responsibilities require both time and skill, and can take an extraordinary toll on parents' physical, emotional and psychological health (Kirk, 1998; Bradley et al., 1995). A number of service delivery issues affect the well-being of children and families, including respite care, education, recreation, child care, health services and transportation.

Respite

The ongoing care of children with disabilities or those who are chronically ill can be an overwhelming and stressful task. As children are now likely to live at home with their families, rather than in more institutionalized environments, considerable attention is being paid to the need for caregiver relief by fostering the development of respite services (Joyce et al., 1983). There is a large body of literature addressing respite care for families (Cotterill et al., 1997; Joyce et al.,1983). However, despite

continued attention, Hays, Hollander, Tan and Cloutier, (1997) found that issues related to respite care have changed little in the last 15 years. Respite care remains important in promoting well-being for families and encouraging community inclusion of children. But public policies have not yet adequately addressed the long-evident issues that families face in accessing appropriate and affordable respite care.

Simply put, respite services give parents or guardians time off from caregiving. There are a variety of forms that respite can take, both within and outside the home, including local services, emergency support and holiday or weekend service provision (Cotterill et al., 1997). In-home respite care may include, for example, homemaker services where trained individuals perform short-term services such as teaching or training; informal support provided by sitter companions possibly known to a child and home interventions that include a range of semi-professional services. Out-of-home respite care may include institutional respite, which, although unpopular, is used for longer breaks such as vacations. Other support measures include family care with a surrogate or temporary foster family, groups homes, or residential respite care centres. Respite care has also been described as including a continuum of services with components including parent training, behaviour management, case management, crisis intervention, family counseling and so on (Hays, Hollander, Tan and Cloutier, 1997).

Regardless of the nature of disability that a child experiences, parents have common support needs. Respite care reduces the burden of care on family caregivers, and results in a significant reduction in levels of stress, strain and burnout for parents (Rimmerman, 1989; Canadian Association of Community Care, 1995; Hoare, Harris, Jackson and Kerley, 1998). Access to needed respite has been found to improve family functioning, reducing the likelihood of marital breakdown, and to improve parents' attitudes toward their child (Canadian Association of Community Care, 1995; Hoare, Harris, Jackson and Kerley, 1998). As a result, not only is a child less likely to be institutionalized, but the child and his or her family members (especially primary caregivers) experience reduced social isolation, increased independence, a wider range of activities, improved well-being and social integration in the community (Cotterhill et al., 1997; Hoare, Harris, Jackson and Kerley, 1998). Respite care has been especially beneficial for mothers who tend to be the primary caregivers. Mothers are better able to enter or maintain their status in the workforce, and they indicate more positive interactions and experiences within their families (Grant et al., 1998).

Despite the importance of respite supports to the well-being of women, children and families, the need for good, flexible respite care is still not being met (The Roeher Institute, 1999, Metropolitan Toronto District Health Council, 1997), and the need is likely to continue to grow (Caledon Institute, 1997). Overall, problems associated with respite care include a lack of well-trained caregivers, the fragmented and uncoordinated organization of respite services and poor financing (Hays, Hollander, Tan, and Cloutier, 1997).

One of the main access issues is geographical location of services. Families who live in rural areas have less access and less variety of services to choose from than those living in urban centres. Cotterhill et al. (1997) also found that families were restricted by exclusionary eligibility criteria, and by the extent of their child's support needs. Similarly, the Metropolitan Toronto District Health Council (1997) found that out-of-home respite programs generally do not accept children who use ventilators, require one-on-one support, or who have behaviour disorders. Hoare, Harris, Jackson and Kerley (1998) found that families with low incomes, and those who are visible minorities,

have less access to such services. As a result, waiting lists for respite services are common.

Models of respite from which families can choose remain unnecessarily limited. Respite services have been criticized for their lack of flexibility, arbitrary limits on service use, failure to respond consistently to crises, and for their high cost when given in a private setting (Knoll and Bedford, 1989; McKeever, Angus and Spalding, 1998). Inadequate training of respite workers, lack of availability, high turnover rate of staff and inattention to the family's wishes and privacy needs (Cotterill et al., 1997) have also left in-home respite care open to criticism.

Some of the problems associated with respite care, and particularly in-home services, can be attributed to the way labour in this sector is organized. Parents and children often have little choice regarding how, when, and by whom, respite care services will be delivered. For example, while many prefer in-home services, they must rely on out-of-home services. Furthermore, families consistently report that they do not receive enough respite care (Hays, Hollander, Tan and Cloutier, 1997). However, there is a dearth of literature available outlining the requirements of respite care services, the organization of respite care labour and issues related to high turnover, worker satisfaction, wages and job security.

Education

A child's primary education experience has an immediate impact on the demands of parents caring for children with disabilities. Children with disabilities participate in a range of educational programs that might include full- or part-time attendance; the use of teacher aides; full- or part-time special classes, or segregated school placement; full- or part-time integration in mainstream classrooms; or full inclusion in regular classrooms with same-age peers. Schools may also offer therapeutic services such as speech or physical therapy (Hays, Hollander, Tan and Cloutier, 1997), but these services are not universally available.

Inclusive education is more and more popular among parents, who see public education in regular classrooms with same-age peers as a right that contributes to lifelong community inclusion (The Roeher Institute, 1997). The concept of full inclusion demands that students with disabilities be educated in the same setting as their peers, with appropriate supports "rather than being placed in special education classrooms or schools" (Mesibov and Shea, 1996:337). Ambivalence toward inclusion is linked to limited education and expertise on behalf of professionals regarding various disabilities. Training educators about inclusion has become a major point of controversy (Hays, Hollander, Tan and Cloutier, 1997). Mesibov and Shea relate parental frustration with educators' lack of knowledge, resources and commitment to inclusion, and the resulting impact on parents' daily interactions with the education system. As well, provincial education policies remain inconsistent. They tend to allow, but not require, the inclusion of students with disabilities in regular classrooms. As a result, inclusion has been interpreted in different ways by different administrations (The Roeher Institute, March 1997). Schools that are committed to inclusion and have the resources to fulfil this mandate demonstrate success and have a direct impact on the well-being of children and their families.

A common barrier to policy implementation is the difficulty in merging the interests of administrative and professional groups on the one side with the deprofessionalizing, devolutionary pressures inherent in inclusion on the other. In their international review of inclusion policy, Loxley and Thomas (1997) suggest a number of issues that limit effective implementation of inclusive education:

- There are inconsistencies between

educational policies, and a general lack of continuity in needed in-school supports.

- Educational policy is excessively procedural. A great deal of time and effort is spent administering a special education system that could otherwise be spent on teaching children in regular classrooms.
- Centralization and decentralization pressures conflict in the education system presenting problems in clearly defining decision-making responsibility for formulating and implementing inclusive educational policies.
- The system is limited in its openness to the direction and input of parents in the decision-making process about placement of a child.
- There is a lack of stability and continuity in professional support services.
- Educational concerns are driven by resource availability and financial concerns, more than by a policy commitment to inclusive education.
- Questions persist regarding the extent to which policies focus upon the needs of parents and pupils, and how closely services actually meet their needs.
- It is unclear to what extent policies promote the continuation or the discontinuation of dual systems (between special and mainstream education) in both administration and in service provision.

It is clear that concrete models for administrating student-centred curriculum, supports and services (teachers aids, speech, occupational therapy, physical therapy, vocational training and the like) need to be developed. Furthermore, resources are required to implement these, and teachers need access to education and training in both disability and inclusion. These factors are integral to the success of children and parents (Middleton, 1999; Loxley and Thomas, 1997; Mesibov and Shea, 1996).

Early childhood education can play a positive role in a child's development. The advantages of early intervention for children with disabilities have been well documented (Mackenzie-Keating and Kysela, 1997). The support provided to parents by such programs also has significant impact (van Gennep et al., 1997). Sayeed and Acton (1997) describe early intervention, ideally, as initiating the experience of inclusion. In a similar vein, Wesley et al. (1997) outline how the opportunities for dialogue and collaboration between parents and professionals at this early stage may be the foundation for enriching collaborative partnerships and the promotion of shared decision making in design, implementation and evaluation of early childhood services.

Recreation

Recreation and leisure opportunities are key in fostering community inclusion. How they are organized also affects caregiving demands on parents. They are important in developing social networks and "leisure identities" (McGill, 1996). Perrin, (1989), in a report presented to the Ontario Ministry of Community and Social Services, discusses a number of barriers to participation in leisure. Of particular relevance here are lack of income, lack of transportation, inaccessibility of leisure opportunities and services, lack of necessary support services and the limited participation of persons with disabilities in the planning and implementation of recreation services and segregated programs and services. Furthermore, communities still lack full commitment to inclusion. This is evident in limited initiative and imagination in terms of design and implementation of community recreation programs. The Perrin report further recommends that training should be provided to both recreation providers and to support workers. Ministries responsible for travel, recreation and leisure, for community and social services, and for post-secondary education have responsibilities in this area.

Child care

Like other parents, parents of children with disabilities need and use a variety of types of child care. Those with pre-school age children need access to nursery schools and day care centres. Those with school-age children may need day care before or after school, especially if they are working. However, there is no comprehensive system of child care in any province or territory, despite rising numbers of women working outside the home, and a decline in extended family support because of shifting family and community patterns (The Roeher Institute, 1999). The Childcare Resource and Research Unit (1997) found that regulated child care provided for less than 8% of children under the age of 12 in Canada, though workforce participation for women with children under the age of 6 is 65% (The Roeher Institute, 1999).

In many provinces, access to day care is actually decreasing. The Ontario Coalition for Better Childcare (1998), for example, reports that in Ontario, 9,000 child care subsidies have been lost, and 71 day care facilities have been closed in Toronto alone since 1995. This occurred when 50% of costs for day care were downloaded from the province to municipalities, a process that failed to account for costs for inclusion of children with disabilities, and resulted in higher user fees for parents with subsidies. At the same time, the Coalition adds, the requirement that schools include day care has been reversed. Thus schools are not required or funded to provide Junior Kindergarten, and in a number of cases, such programs are being cancelled.

While families in general face difficulties accessing affordable, quality day care, those that have children with disabilities face even greater barriers. Inclusion of children with disabilities in day care is voluntary throughout the country. Most provincial governments support this policy goal to some extent, but they do not require it (Hope Irwin and Lero, 1997). It is estimated that in 1996 most child care centres supported some children with disabilities some of the time. However, they did so on a child-by-child basis, accepting or excluding children on a discretionary basis (Hope Irwin and Lero, 1997). In 1991, 12% of children 4 years of age and under, who had disabilities were refused the service (The Roeher Institute, 1999).

Even when parents are able to access a designated "integrated" program that is licenced for special programming, these programs are criticized for their inflexibility (Ontario Coalition for Better Childcare, 1998). The ability of mothers to find good quality community day care for their children with disabilities is hampered by limited staff training and lack of technological and staff resources (Bowman and Virtue, 1993). Further, facility-based child care programs often have eligibility criteria that disabled children may or may not be able to meet. For example, they may only accept children who can use the toilet, walk or communicate verbally.

Accessible, integrated after-school, pre-school and day care are integral to both children's and mothers' well-being. In a number of studies and first person accounts, limitation in child care has been named as one of the main barriers to work force participation for mothers (Bowman and Virtue, 1993). Current child care policy, or more rightly the lack of policy, is not addressing this issue in a comprehensive way. Furthermore, children need the social experiences afforded them in such settings (Newman and Tyler, 1991).

Health services

Current health care policy for home care supports has a number of impacts on the well-being of families that include children with disabilities. In response to new directions in health care, policy is now

concentrating on expanding current home care initiatives and developing a broader array of supports and services for those being cared for at home. Costly hospital care is being replaced in favour of community care. However, a comprehensive system of supports and services is not in place. The supply of community-based health services is not meeting the demand, and families are currently picking up the slack (Canadian Association for Community Care, 1995; Anderson and Parent, 1999).

The literature suggests that families would benefit from a comprehensive home care program with several components in addition to acute care services. These include technical aids and equipment, attendant services, homemaker services, respite care, brokerage and information and referral services (Torjman, 1998).

The relationships between families and health professionals also affect children with disabilities and their parents. Professionals can evoke strong ambivalent feelings from parents. A report out of the University of Western Ontario, titled *Family Physicians and Persons with Developmental Disabilities* (1993) found that children and adults with intellectual disabilities, and their families and caregivers, have significant difficulty in accessing appropriate health services. Family physicians provide services to them with variable confidence, enthusiasm and ability. Family physicians tend to have little or no basic educational preparation regarding the issues faced by these patients, and their access to support systems for education, service and encouragement vary.

Parents can experience indifference, inconsistency, ignorance, paternalism, support, openness and/or empathy from health professionals (Seligman and Darling, 1997; Haverstock, 1992). Dealing with professionals who are knowledgeable about disability issues, who understand the perspectives of individuals and their families and who involve parents in the provision of health care needs is vital to parents (Wilgosh and Chomicki, 1991). Parents also need better access to reliable local health services, especially in rural areas. For children with complex medical needs, in particular, accessibility to pertinent local services is integral to their ability to live at home and thrive in the community.

With the move to community health models, specifically home care, it is critical that professionals entering homes to offer support be cognizant of the values and beliefs of the family whom they wish to help. Support must be offered on the family's terms, which may often conflict with present models and the limited array of supports that are offered (O'Connor, 1995). For example, the variability in parental roles can be a source of conflict between parents and professionals. In some intervention models parents are asked to take on more of a teaching role for their child, and for some parents the required training may interfere with the desire to develop a more natural relationship with their child. It is important that professional expectations not circumvent parental rights and desires (Seligman and Darling, 1997).

Transportation

Literature regarding transportation issues is minimal at best, and yet transportation is critical in addressing inclusion and issues of well-being. In their evaluation of a number of family support programs, Bradley et al., (1992), reported that in all of the different support plans, expenditures for transportation were near the top of the lists of needs. In fact, families incur great cost when they care at home for children or adults with disabilities, and transportation costs are often a good part of a family's increased financial burden (Fujiura et al., 1994).

Transportation is key in the implementation of quality supports and services, and yet it is often marginalized by program and policy

designers (Katzmann, 1986). A good transportation system can play a role in overcoming the isolation that is common both for those providing and receiving care in the community. A report on transportation in Ontario by the The Ontario Advisory Council on the Physically Handicapped and The Advisory Council on Senior Citizens (1989) recognized that "both physical and attitudinal barriers must be removed since lack of accessibility to transportation services not only creates a handicapping environment, but also perpetuates systemic discrimination and segregation of many people in this province."

There is not only a need for increased, accessible public transportation, but also for a greater recognition of the transportation component of services provided by agencies and organizations. In the development and budgeting of programs, transportation is often inadequately funded and is often assumed to be a volunteer consideration. Without transportation an abundance of services and supports would be inaccessible. In fact, even when transportation is available, its cost prohibits some from using it as much as they may want to (Ontario Advisory Council on the Physically Handicapped et al., 1989).

Socio-economic Factors Affecting Children and Families

Employment

The time commitment and ongoing stress of caring for children with disabilities can limit the labour force participation and positive work experience of parents, while workforce commitments and stresses can affect parents' capacity to care for their children. Since mothers are up to ten times more likely to be defined as caregivers of their children with disabilities than fathers (Bowman and Virtue, 1993; The Roeher Institute, 1999), they are less likely to participate in the labour force. When women do participate in the workforce they tend to fit it in around family commitments, working part-time and/or on weekends. According to a study by Irwin and Lero (1997) 39% of parents whose children were disabled worked reduced work hours, 46% worked altered schedules, 68% turned down overtime and 72% passed up promotions because of their caregiving responsibilities. While this flexibility can be seen as advantageous, it is really a double-edged sword, since it brings disadvantages in terms of pay, pension contributions, sick leave and vacation pay.

It is not just the responsibilities of child care that have an impact on women and their participation in the workforce. The structure and organization of the workplace also has an impact on their caregiving and job retention. In a Roeher Institute study, parents said they needed flexibility in the workplace to balance their occupational and home responsibilities when they have children with disabilities. The kind of flexibility they need relates to control over hours of work; the ability to schedule meetings appointments, and so on, when convenient; access to benefit packages even if working reduced hours; allowances to accumulate overtime in order to take time when needed; options for working from home and freedom to go to their child immediately, if needed (The Roeher Institute, 1999). However, many said flexible work was hard to find. Its absence often leads to transitions from full- to part-time work; from professional positions to support positions requiring less commitment; from employment to unemployment and from employee status to self-employment (The Roeher Institute, 1999).

Furthermore, a number of parents find juggling work and caring for a child with a disability so stressful that they decide one spouse must choose to leave the paid workforce and stay at home and care for their child full time. In one study, 64% of two-parent families that included a child with a disability reported one parent losing

or giving up his or her job to provide supports to their child (Irwin and Lero, 1997). It is frequently the mother who stays at home. As a result, she may face considerable consequences related to her security, including reduced income, loss of pensionable earnings, stress and isolation from staying at home, loss of career opportunities and challenges upon re-entering the workforce (McKeever, Angus and Spalding, 1998; Ambert, 1992). The career mobility of fathers is also affected, though to a lesser degree. For example, some fathers have reported declining promotions that would require moving the family away from available supports and services (McKeever, 1981).

The research shows that a lack of affordable quality child care for children with disabilities is a major barrier to employment. In a recent study by The Roeher Institute (1999) parents reported that factors that would facilitate employment include the availability of child care and respite care, and comprehensive, flexible and quality services.

Costs associated with disability

Parents of children with disabilities are more likely to be living on low income than other families. Rates of disability are five times higher among families with lowest income compared to highest income (McKeever, Angus and Spalding, 1998). Parents also face additional financial costs related to disability. As outlined above, parents, especially mothers, face reduced income and related benefits because of the time lost from employment that is spent on caregiving, managing care and advocating for services. They also may incur additional costs for tutors special diet, special clothing, transportation, babysitting, medications, supplies and equipment, and home adaptations (McKeever, Angus and Spalding, 1998; Ambert, 1992). According to American researchers Fujiura, Roccoforte and Braddock (1994), the annual average income for an American family is $37,657. They estimate that families of children with disabilities pay a significant proportion of this for disability-related, out-of-pocket expenses (an estimated $6,348 in their study). They also found that the percentage of household costs increased significantly as family income decreased. The researchers reported that these were higher expenditures than those for families without children with disabilities.

Gender and unpaid caregiving

While the language in the literature often uses the term "parents" when discussing the caregiving role, it is well documented that in the majority of families mothers are the primary caregivers of their children. Indeed, the 1996 Census data shows that women tend to take on the bulk of unpaid work in communities, and much of this is in caregiving (Status of Women Canada, 1998).

This trend gives rise to a number of concerns. The first is why women continue to perform the bulk of unpaid labour in communities. Contemporary feminists are critical of the idea that women share some common trait that makes them most suited to be nurturers and caregivers. Social, economic and cultural pressures socialize women to fulfil these roles, that is, to become nurturers and caregivers (Haraway, 1991).

McKeever, Angus and Spalding (1998) outline how notions of women as caregivers form the basis for health and welfare policy, and that the negative effects on women are on the rise. Escalating health and social services costs are leading to a mixed economy of care in which long- term care facilities are being closed or converted to provide outpatient or ambulatory care centres, and community-based services are replacing institutions. Community-based services, however, are not keeping up with the demand. Families are expected to fill the gap by carrying out previously waged

caregiving duties at home without pay. "Family care" and "home care" are often used as euphemisms for care by women. Women are censured if they reject the role. Instead, they forgo opportunities to fulfil these responsibilities, and thus, the authors warn, compromise their citizenship.

A number of studies describe caregiving tasks as hard work requiring the combined professional skills of nurses, teachers, therapists and administrators. Mothers often make a "career out of caring" (Wickham-Searl, 1992). In fact, they perform many skills that were formerly in the realm of paid professionals. Mothers manage complex intra- and extra-family relationships, monitor children's conditions, perform custodial, therapeutic and medical tasks, schedule appointments, act as advocates and more (Haverstock, 1992; Ambert, 1992; McKeever, Angus and Spalding, 1998). Despite all of this, their work is neither granted professional status, nor is it compensated through payment, or other opportunities. Women in this position are part of an invisible work force. They are unpaid, considered unskilled, have no vacation leave, no sickness benefits, no workers compensation, and no safety standards. Furthermore, they work on call constantly and live where they work (McKeever, Angus and Spalding, 1998; Ambert, 1992; Guerriere and McKeever, 1997).

Not surprisingly, this state of affairs has a significant impact on women's health and well-being, as well as on their social and economic opportunities and sense of security. As was outlined earlier, their participation in the paid labour force is delayed or severely restricted by the demands of caring for a child (The Roeher Institute, 1998; Booth and Kelly, 1999). It also has a negative economic effect on society more generally. Bakker (1998) describes some of the hidden social costs that arise from unpaid work including loss in women's time use and opportunity, tax contributions, and increased demand on social services. The cost of caregiving is an area that continues to need attention at the policy level. However, caregiving activities are difficult to cost and measure. Caregiving activities are ongoing, and they overlap with each other. They are not linear, but are balanced with other family and domestic responsibilities, and are frequently interrupted by them (McKeever, Angus and Spalding, 1998).

Regardless of the difficulties in measuring caregiving tasks, the impact is clear. Mothers of children with disabilities are described as anxious, sad, burdened, exhausted, socially isolated, lonely and lacking in self-esteem (McKeever, Angus and Spalding, 1998). They report high physical and psychological stress, chronic fatigue, headaches, menstrual problems, digestive problems, depression, anxiety, interrupted sleep and irritability (Ambert, 1992; Guerriere and McKeever, 1997; McKeever, Angus and Spalding, 1998). The literature is contradictory, however, regarding whether or not they experience these problems to a greater degree than other mothers. McKeever, Angus and Spalding (1998) suggest that these problems are more prevalent in mothers of children with disabilities than other women. They report, for example, that 40% of this group have trouble sleeping, compared to 28% of other women. Mothers of children with disabilities also exhibit the highest consequences in terms of emotional and physical stress (Bowman and Virtue, 1993; Traustadottir, 1988). Other studies, however, described in a review of the literature by Hoare, Harris, Jackson and Kerley (1998), show that the overall distress of mothers with and without children with disabilities is comparable. These studies suggested that the mothers experiencing highest distress have low incomes, regardless of disability. In their own study, however, these same researchers found that mothers' distress was associated with the severity of disability, increased dependency, profound locomotor disability, incontinence and sleep difficulties of their children.

There is a growing body of research that is looking at the differential implications of caregiving issues for women and men. The role, responsibilities and impacts on fathers are treated with some contradiction in the literature. Most of the literature suggests that women perform the bulk of caregiving responsibilities, generally. Willoughby and Masters Glidden (1995) suggest this trend is in fact exaggerated in the case of fathers whose children have disabilities, even when mothers work. McKeever (1981), however, found that fathers report sharing responsibilities equally with their wives. While census data supports the findings in the literature that women carry the bulk of unpaid caregiving responsibility, very few studies have explored fathers' perceptions of their roles and responsibilities. Most of the research available explores the experiences of female caregivers.

A small body of research examines the impact of fathers' participation in caregiving. One study suggests that when fathers do participate, both partners express greater marital satisfaction, and both report greater psychological health (Willoughby and Masters Glidden, 1995). In McKeever's (1981) study of fathers of children with disabilities, fathers, like mothers, reported social, health and economic consequences including reduced participation in community activities, stress, worry, and health problems such as headaches, ulcers, anxiety, hypertension and obesity.

In considering these impacts on mothers (and fathers) it is important to note two other factors. One is that while much of the literature focuses on negative impacts, mothers also describe the great benefits experienced when parenting a child with a disability. Care is described as deeply rewarding and satisfying (McKeever, Angus and Spalding, 1998; Ambert, 1992). Parents report finding a "new appreciation for life" through their relationships with their child (Guerriere and McKeever, 1997). Wyngaarden, Krauss and Mailick Selzer (1993) outline the positive effects mothers of adult children with disabilities describe. In this study, mothers developed adaptive coping skills, such as acceptance, positive reinterpretation and growth, spiritual strength, and planning skills. They were described as women who actively engage with life's problems.

The other important point to note is that the negative impacts experienced by mothers are not caused by their child. Women clearly attribute problems such as isolation to barriers in community and withdrawal of relationships and support from friends and family (McKeever, Angus and Spalding, 1998). Furthermore, they perform their role within a service system that is fragmented, often inaccessible, inconsistent in commitments to inclusion, limited in choices and peopled by professionals who often have a limited understanding of disability (Hoare et al., 1998; Sharpley et al., 1997). As is evident in the earlier sections, it is lack of access to services such as respite and child care that restricts women's opportunities and contributes to their distress. That this may also be true to some degree for mothers of children who do not have disabilities does not detract from the urgent need for these issues to be addressed. Rather, it points to the broad applicability of solutions such as affordable and accessible day care.

It is important also to recognize that women do not constitute a homogeneous group. Rather, women are variously positioned along the lines of disability, race, class, age, sexual orientation and ethnicity. Therefore, a host of social circumstances related to systemic disabilism, institutionalized racism (Vernon 1996; Stuart 1992), heterosexism and homophobia (Tremain, 1996b; Appleby, 1994; Hearn, 1991) confront women in their role as caregiver. These issues need to be recognized and addressed in social policy, as well.

Given the profound impacts on mothers caring for children with disabilities, McKeever, Angus and Spalding (1998)

recommend that policy conceptualize caregiving as work so that compensation and working conditions can be considered. Policies that do not do this, they suggest, punish women for providing care at home. One strategy they suggest is to have programs with occupational health components, such as lifting techniques for parents. Another is to improve working conditions through funding adequate home adaptations and amenities. Their research finds that respite, emergency and vacation care are essential. Policy-makers also need to pay attention to, and address circumstances that require women to perform the bulk of unpaid work involved in caregiving.

IV.
RESEARCH FINDINGS

Mothers and Families Included in the Study

This section reports on findings from interviews with 50 mothers caring for their children at home — 17 women from Ontario, 12 from Manitoba, nine from Saskatchewan, eight from Quebec and four from New Brunswick. The majority of families (60%) lived in urban centres (Winnipeg, Saskatoon, Montreal, Ottawa, Toronto and surrounding areas). The remaining families lived in small communities or rural areas.

Family characteristics

The majority of families were headed by two parents. Nearly one-quarter were single parent homes. In all of these homes, mothers were the primary caregivers. Mothers ranged in age from 20 to 54 years. About half of these mothers worked outside the home, with approximately 30% working full time. Most of the families were white. Only 6% reported visible minority status.

Economic situation

The monthly income reported ranged from $1,100 to $8,000, with an average family income of just over $3,300 per month or $39,600 per year. Employment earnings were the main source of income for families (84% received earnings from employment), while only one family relied primarily on social assistance.

Employment earnings	Percentage
Under $20,000	21.6%
Between $20,000 and $30,000	16.7%
Between $30,000 and $50,000	43%
Over $50,000	29.1%

Types of disabilities

The children referred to in this study have a variety of disabilities. In fact, the majority of children (90%) have multiple disabilities. The following disabilities affected children in this sample:

- 80% had a disability that affected learning or the ability to process information
- 80% had a disability that affected speech
- 72% had a disability that affected mobility or agility
- 50% were visually impaired
- 34% had a disability that affected mental health
- 24% were hearing impaired.

Personal Accounts

While the situations of families are quite varied, the impact of non-responsive or inadequate services and supports was common. The following accounts depict some typical family experiences in caring for children with disabilities. While these vignettes are drawn from study participants, names and other details have been fictionalized.

Susan's family

Patty lives on a farm with her spouse, Doug, and her 8-year-old daughter, Susan. Susan has cerebral palsy and an intellectual disability. She has high support needs, requiring about 18 hours a day for personal care. This care is provided by her parents and paid support providers.

Doug works full time, and Patty has just gone back to work. Even though it takes a lot of time and energy to coordinate all the services needed to support Susan, she could not stay at home any longer. Not only do they need the income, but Patty sees her job as important for her mental health. Patty and Doug are currently remodelling their home to make it more accessible for Susan. In addition to the hours spent on daily personal care, Patty also spends an average of 17 hours per week advocating and coordinating supports and services for Susan. This does not include the hours spent in transportation to various programs or appointments.

David's family

Having left an abusive relationship, Donna is trying to support herself and her ten-year-old son, David. They have just moved to the city from a rural area, and the city is unfamiliar to them both. They moved because Donna realized that David, who has cerebral palsy, would be better supported in an urban environment. Donna spends a large part of her day providing personal care for David and is currently able to handle the physical demands. However, she worries that her capacity to do this will decline as David gets older. Donna works full time and David goes to school. As a student at "one of the two schools in the city totally committed to inclusion," David participates in an environment where he is welcome and where issues of disability are discussed openly. After school, he receives respite care in the home because the family could not access appropriate inclusive after-school care. Because she had to work, Donna accepted respite services in the home, although she would prefer a more social environment.

Along with the struggle for day care, Donna has found similar struggles in other areas of the community. Not only are there limited recreation and leisure programs that are accommodating of his needs, David cannot get into the local arena to see a hockey game or any other entertainment. They cannot afford many other community recreational or therapeutic programs. On top of working full time, and spending an average of four to six hours a day on personal care for David, Donna currently spends approximately 10–15 hours per week coordinating David's week and advocating for a more inclusive and accessible community.

Jody and Lee's family

Jody and Lee are brother and sister, and they both have disabilities. They live with their parents, Pam and Greg. This family is well off financially. Greg has a job that pays well, and Pam does not work outside the home. She has made caring for and supporting her children her career. Paid staff support Pam in the daily care of Jody and Lee. The family can also afford to pay for the needed physiotherapy, speech therapy and life-skill training not provided through health, education and/or social programs.

While they can afford many of the supports and services they need, they are still frustrated by barriers to community inclusion for their children. For example, they still face struggles with education and health professionals. Also, their families are not very accepting of Jody and Lee, and it is hard to include them in family functions. These children are still not integrated into the community for a number of reasons. First, they use mainly private services. Also, the time required to seek out and coordinate all of these private services takes away from school and community activities. While this family can pay for community experiences, these experiences are not with the children's peers, they are with paid staff who can take them into the community, but cannot provide for natural social experiences. Pam finds that coordination and transportation related to these private services and community activities take an enormous amount of time and a considerable personal toll.

Caring for Their Children

Mothers are the primary caregivers.

Nearly all of the mothers interviewed (96%) were the primary caregivers for their children. Mothers spent, on average, 3–4 hours per day doing hands-on personal care (bathing, toiletting, feeding, providing medical care) for their children. Almost all children required additional support, such as assistance with communication, supervision or help dealing with behavioural issues/concerns.

Mothers spend considerable time caregiving.

The mothers who had children with disabilities affecting their speech, spent on average two hours more per day providing personal care and were spending more than twice the average time as other mothers in extra support around communication and/or behaviour per day. This means those whose children had a disability affecting their speech spent an additional six hours per week providing extra support, while other mothers spent less than half that time providing additional communication/behaviour support. This may be because children with a disability affecting their speech tend to have more severe disabilities and consequently a higher need for support, or because communication difficulties in themselves require more time and attention.

In addition to time spent providing personal care, mothers acted as advocates, coordinators of care, and providers of transportation to school, child care, generic and specialized health services, therapies, recreation and leisure for their children. The vast majority spent considerable time in these activities. Nearly all of the mothers (85%) report playing the role of advocate for their child, spending an average of over four hours per week in this capacity. Over 90% provided

personal support for their children for an average of almost 11 hours per week. Coordinating services and supports was also a role played by most mothers (over 90%), usually for over seven hours every week. More than 90% of mothers provided transportation, spending almost six hours per week doing so. All in all, mothers reported spending an average of almost 30 hours per week in these tasks, in addition to the 20–30 hours per week they provide in personal care for their children in the home. Providing support to their children with disabilities is clearly more than a full-time job for most women, requiring between 50–60 hours per week of their time, in addition to their other workforce or domestic responsibilities.

Mothers played a variety of roles.

Mothers play a variety of roles in the support of their children. They provide transportation, advocacy, personal support, service coordination and therapies. They deal on an ongoing basis with a wide range of professionals, often teaching professionals about how to include their children in activities in the community. Despite these busy schedules, some mothers also found the time to volunteer with an agency or organization that was relevant to their children's inclusion in the community. Over 70% of those interviewed report doing volunteer activities of this sort.

Playing all these roles is not easy: "Trying to balance all these services is incredibly hard. The barriers need to be broken down so I do not have to do it." On the positive side, mothers developed new skills and confidence, and discovered a lot about themselves in the process: "[Having a child with a disability] is the most wonderful thing that's ever happened to me. I found talents and strengths that I did not know I had. [My child] makes people change...life is a never-ending adventure." Mothers found it hard to measure how they spent their time, however. It was especially difficult to distinguish time spent on different aspects of care (i.e., advocacy versus coordinating services). They do not necessarily perform these tasks at separate times. They may do more than one thing at a time, or with frequent interruptions by other demands.

Spouses provide limited support.

While 80% of the participants were married or had partners in the home, just over 60% of them had daily help from their spouse (or another family member). When spouses did participate in caregiving, they tended to do so in the evening. However, quite a few of these women had spouses who worked late or long hours, so they were alone in the provision of evening care as well.

Women received limited unpaid caregiving support in their communities.

While women received some support from their spouses, very few had friends, neighbours or extended family supporting them in this care. In fact, less than 25% of the women surveyed had extended family supporting them and this was at best weekly or a few times a month. It would appear that families are not only isolated within the community, but from extended family as well. A few women commented on the inability of extended family to feel comfortable in the presence of their children with disabilities.

Although mothers did not tend to receive regular help from family and friends, many did, however, feel they could go to them for help if they had to. When asked if they could not perform their caregiving role for some reason, over 70% felt they could count on a family member to step in, and 20% felt they could rely on friends. Only 12% felt they had no one to turn to should such a situation arise.

Some support was received from paid staff.

Over 60% of the mothers reported receiving support from paid staff. Paid supports provided personal care at an average of 2–3 times a week. A very few of those surveyed had access to paid support on less than a monthly basis. In addition, nearly half (44%) felt that if for some reason they could not perform their caregiving role, paid staff would be available to provide the service.

The majority of mothers surveyed also reported involvement with 3–5 community agencies or organizations in supporting their children. The services included information about disability and support options (96%), support services (92%) and advocacy (85%).

Some received support through a parent group or network.

More than half of the respondents (56%) reported belonging to a parent support group or network of parents of children with disabilities. Of those who did not, over 40% said they would like to join one. Most were aware of a parent group that they could be a part of if they chose to (75%). It is difficult to tell if the findings in this area can be generalized outside of the sample, however. Most of the interview respondents were contacted through advocacy organizations and support groups, so it is not surprising that they are members, or are at least aware of these organizations.

Mothers are not satisfied with the support they receive.

Over 70% of respondents were dissatisfied with the amount of support they are currently receiving. Furthermore, 90% of these women stated that the top two things they need the most to support their children in the community are not being met. The most common need was adequate, flexible respite services provided by trained and committed personnel. As one mother stated: "There is no continuity of care. I have to train each new worker to use a feed pump."

Mothers of children whose disability affects their speech or mental health spent more time providing personal care to their children than other mothers. Not surprisingly, they were the least satisfied with supports provided in the community. It is unclear whether they were dissatisfied with the quantity or quality of supports provided. However, this is evidently an area that needs further investigation. Their dissatisfaction points to a clear gap in services for children with speech or mental health disabilities. It should be noted that since a majority of children (80%) had disabilities that affected their speech, this service gap occurs for a high proportion of families. In addition, since children with certain types of disabilities, such as autism and brain injury, for example, were the most likely to have mental health difficulties, they are a group that also appears to be inadequately served. While further investigation is required to determine what exactly is happening in these instances, the findings point to a need to explore in more detail the support needs of children with speech and mental health disabilities, especially those with autism or brain injury.

Labour force participation

Mothers' participation in the paid labor force was limited.

Not only were mothers in this study spending considerable time providing support to their children, 60% were in the paid work force. Of these, just over half were working full-time hours. Those who did not work full time felt that not working, or working reduced hours, put quite an economic strain on the family. However, they felt they had little control over the situation. Most felt they would not have chosen to stay at home to raise their children, had they had a

choice. Some of these women saw work as a way to get out of the house, and while they admitted work could be stressful, they said it was a different kind of stress and that tapping into a network of co-workers might be of benefit to them. A number of women commented that they would like to begin work, or get back to work but could not see that happening given the amount of time and energy required to care for their children. In fact, almost 90% of those not in the paid labour force cited caregiving responsibilities as a reason they were not looking for a job.

Child care responsibilities impeded labor force participation.

Child care responsibilities were reported by women as a major impediment to labour force participation. For example, of the mothers who were working part time, almost 80% indicated this was the reason for their choice. As one mother stated: "I took time off without pay. I was told to make a choice between my family and my job. I have gone to half-time in my job, and took a year's leave of absence." Mothers also left jobs in order to meet their children's needs. In fact, over 60% of those who stopped working after giving birth said it was to care for their children, and over 50% had left the workforce at some point to care for a child with a disability. Over 35% had changed jobs, or reduced their hours to meet their children's needs. There is some indication that fathers may also experience employment difficulties. One woman explained how she not only experienced some censure for time off, but her spouse also "lost three jobs last year as a direct result of child care issues."

Qualities of the workplace affect women's capacity to retain employment.

The qualities of the workplace appear to have an impact on mothers' capacity to balance their work and child care responsibilities. As is evident from the above quotes, parents may be pressured to leave work if they have to take time off to provide care to their child, and punished for the time they need to take. They may, for example, lose work hours ("suddenly there was a lack of available hours for me...") or lose their job entirely. Over 30% of the women reported having encountered difficulties with employers, educators or trainers because they had a child with a disability. Even this may underestimate workplace or training barriers since many had not gone back to work or school following the birth of their child.

Others had more positive experiences with employers. While most women stopped working or reduced the number of hours they worked, some were able to fulfill both responsibilities. For the women who were able to do this, their capacity may have been enhanced by a supportive work environment. All of the mothers who do work full time have employers they consider very supportive and understanding.

Mothers felt their unpaid caregiving activities were not recognized.

Some women looked at the care they provide as a 24-hour-a-day job, and were disappointed that this was not recognized through remuneration: "They will pay a stranger $8 an hour, but not myself or his siblings and there is no pension for me after the years of care I will be providing."

Impacts on health and well-being

Mothers' health and well-being were compromised by their workload.

When asked to rate their health on a scale of "poor, fair, good, very good or excellent," most women (44%) rated their health "good" with 38% rating it "fair." Only 12% of the mothers rated their health as "very good." In contrast, the National Population

Health Survey (1996) found that significantly more mothers rated their health as very good (40%) and fewer rated their health as merely good (26%) or fair (6%). In other words, mothers of children with disabilities in this study were less positive in reports of their own health than mothers in Canada in general.

Over half of the women surveyed (52%) reported that they suffered from anxiety or depression and/or general symptoms of stress. They described experiencing a wide variety of symptoms of stress, including: disrupted sleep, headaches, isolation, stress, anxiety, frustration, fear, anger, agoraphobia, depression, feelings of hopelessness, feeling overwhelmed, ulcer, fatigue, stomach aches, insomnia, hypertension, chronic pain. One woman, in describing the way she feels, said: "I am 42 and I feel like I'm 90."

Women tend to seek support to deal with their stress.

Over 75% of the women needed to seek support to deal with the stress in their lives. The majority (63%) looked to peers for support while some (37%) received medication and others (over 50%) counseling. About half of this group were satisfied with these supports. In one case, a woman had a hard time because her need for support was medicalized. She says: "I have requested counseling supports but got medication instead." Preliminary data suggests, not surprisingly, that the more supports a woman receives, the more likely she is to be satisfied.

Women also described taking the initiative to change their lives to reduce their stress. Some strategies included taking courses, going back to work, and ensuring a "super organization of my life." In one case, a family created a support system for themselves by starting a parent support group:

> *"We have made some good friends and peer support certainly saved our sanity, but there would have been no support if we had not pushed for this group. I had to fight for someone to talk to from the get go."*

Inadequate support has an impact on the whole family.

The time spent by mothers providing care for a child with disabilities had an impact on the whole family. In particular, the variety and persistent nature of caregiving roles had the most impact on stress levels in the home, at work and on other siblings: "The time and energy needed to be an advocate is very stressful...it is my least favourite role because of who I have become and the time and energy taken away from the family." Three-quarters of the mothers surveyed reported that the time and energy these support roles required of them increased the stress and tension in the family at least "somewhat" and almost half said "quite a bit." When asked about the impact on siblings, 70% of mothers responded that their care responsibilities had an impact on siblings at least "somewhat" with 34% placing the rating at "quite a bit" or higher.

Mothers felt that the stress they experienced had an impact on their spousal relationships as well. A number of women reported strain in their marriage. They reported not having time to spend alone with their partner. It was hard for them to do things such as plan holidays. One woman said simply: "We have a limited life." Another mother summed up the issues experienced by families:

> *"The number one thing is the effect on siblings.... the turnover in staff affects them as well, they become attached and their behaviour changes with all these changes in staff.... the support workers are very young and have a lack of maturity and training.... I have to keep track of their hours, find funding sources and find the workers as well, this is quite stressful.... the tension between my spouse and myself stems from the lack of privacy.... it*

is hard to have sex when a worker is 10 feet from the bedroom door.... we also have to maintain a facade in front of these strangers.... the lack of control over how these services are provided and the balancing of these services are certainly stressful as well."

Support issues, not children, cause family stress.

Many of the participants wanted it made clear that it was not the care per se that caused stress, but the frustration and anxiety arising from coordinating that care, and the lack of choice in the way supports and services are provided. One woman emphasizes: "I have to say here that it is not caring for my child that stresses me out, it is the lack of support."

Mothers are concerned not only about the harmful effects of stress on themselves. Many were also concerned that the high stress could force them to place their child outside the home. One mother was at this crisis point, and explained: "I would not be looking at a group home setting for my child if not for the physical and emotional burnout from lack of support."

Mothers have positive experiences caring for a child with a disability.

Mothers are also quick to point out the many positive experiences that come from having a child with a disability. Their experiences as parents of a child with a disability were a great source of strength and growth for many mothers. They report that their experiences have made them better people, increased their awareness of a wide range of issues, made them stronger, taught them "how to fight," and to look at the world and other people differently. They believe they have been given greater insights, learned acceptance, become more sensitive to others' differences, learned new talents, and gained a sense of fulfillment. As one woman explains: "I live life much closer to the bone. I do not get caught up in peripheral things. We are very gifted in life. This can be a very fulfilling life if you are open to the way it changes you." Another says, "I have gotten so much back we have to reconsider what we value. He is an inspiration ... I feel very blessed."

Education

Most children were fully or partially integrated at school.

Eighty five percent of the children with disabilities in this study attend school. For the most part, those who did not were not of school age. Of the children referred to in the interviews, 35% were in primary grades (1–5); 30% were in junior grades (6–8) and 14% were in high school.

While most school-age children were in integrated classrooms with teachers' aids or attendants (67%) for at least part of the day, almost 40% were either attending segregated schools, or were placed in segregated classrooms at least part of the time. Work oriented programs or transition planning tended to be uncommon among high school students. Only a couple were in work co-op programs, and none of the mothers were aware of any school-to-work transition planning taking place.

Many mothers were dissatisfied with their child's education.

Over half of the mothers with children in school were not satisfied with their child's education. In response, most mothers (85%) were engaged in advocacy with the education system on their child's behalf. The most common reason for dissatisfaction cited by the mothers was a perceived lack of responsiveness and commitment on the part of either the teachers, administration or school district to inclusion policies. This translated into a lack of resources, both

physical and human, in supporting children in the classroom. It was, in fact, issues surrounding education that received the most emotional responses:

> *"The last six years have been constant hell...having to fight to get a proper education for my daughter. We ended up having to sue the school and I do not recommend such an action. My daughter now suffers from post-traumatic stress disorder from being locked in a time-out room day after day. The school refused to deal with her any other way."*

Another cause for concern was the physical, occupational and speech therapy that was supplied through the education system. Of the children who received these services, over half of their mothers were dissatisfied with the quality of service (lack of understanding of disability) and the quantity of professional time (sporadic and limited) offered.

Most mothers indicated a commitment to inclusive education, but a few parents had reservations about inclusion, and wanted their children placed in special schools. As one mother said, "I think her aggression would be considered normal in that environment." These parents, however, also pointed to the main problems they had in integrated settings as a lack of resources, and a lack of understanding of disability.

Parents had to fight to get the needed educational supports.

Even those who were satisfied with their child's education pointed out that it was a struggle to get needed supports and acceptance. As one parent summarized, "It took a while to get here ... I had to advocate for more support and class time." Another child had changed schools because the one that he was in simply refused to accommodate him. Another parent said that although things were fine for the time being, there were concerns because "they are not planning for his high school very well."

Many mothers had to play a variety of roles in supporting their children in school and many stated that getting appropriate educational supports was extremely labour intensive. They spent, on average, over 14 hours a week advocating for and coordinating supports, providing support themselves, and providing transportation for their children's education. They worried that budget cuts to education would create even more struggles for them:

> *"The budget cuts to education are a concern. It is frustrating to have to fight all the time. We need government support for education at all levels ... so they can support themselves and become valued members of the community."*

The attitudes of education professionals make a difference.

Satisfaction may be dependent largely on attitudes of education professionals. One parent, after years of struggling with the education system, described the impact of changes in the school staff on the experience of her child: "The principal retired and the teacher left because she had a bit of a breakdown .... the new crew is committed to integration and things are getting better."

Child Care

Pre-school age children were most likely to access child care.

In most instances, families did not access child care services. About one-quarter of children included in this study were enrolled in child care, most of whom were preschool age. Most mothers with the youngest children were satisfied with day care services. However, mothers who had older children were not as satisfied when they looked back on their experiences with day care. It would appear that there have been some gains made in this area.

Child care facilities have limited accessibility.

Parents say their primary frustration with day care is the difficulties they experience finding programs that accept their children: "No child care service would take him." Also, the programs they did find were sometimes not able to meet their children's needs, "the day cares were not accommodating .... the children were younger than him, he had no peers."

Parents experienced barriers accessing after-school care.

Very few parents reported having access to after-school care. In fact, only 12% reported using such services. Those who did use these services were between the ages of seven and 14. Of these, 75% receive after-school care in a private home. Parents of children over ten years of age tended to rely on facility-based care.

Mothers reported a number of barriers to after-school care. In some cases, such services were not offered at their school; the costs of private services were prohibitive; reliable and qualified care was hard to find; staff were not informed about disability; in-home workers were undertrained with limited skills and there was a high rate of staff turnover.

Transportation

Lack of transportation resulted in barriers to inclusion.

Transportation to community services or events was also found to be lacking. Thirty percent of the children in the study reportedly experienced exclusion from community activities because of transportation problems. Under 30% of children accessed any form of transportation support. The main form of transportation used by children, other than that provided by the parents themselves, was the school bus. Very few had used paratransit systems. The reasons given for this were the cost and the lack of availability in rural areas.

Parents tended to provide most of their children's transportation to recreation, leisure or other community activities. Very few mothers used transportation services for their children because they were concerned about supervision, especially for their young children. They had concerns regarding the attitudes of drivers or the inconsistency in levels of service. They said they could not access the system as needed, that times of pick-up and/or arrival are not consistent and that the system is not flexible enough. As would be expected, availability of transportation services is an even more significant issue in rural communities.

Respite

Parents were dissatisfied with the availability and quantity of respite services.

Women reported that appropriate, high quality respite services, in whatever quantity is needed, were most important for supporting their child in the community. However, very few women were satisfied with respite services. Those who were satisfied had a minimal need for respite over and above the occasional evening or weekend. Most parents felt they needed more hours, and access to emergency or continuous weekend supports.

Parents wanted access to flexible, portable services.

Mothers also felt that they needed more flexibility in the way respite care was delivered. For example, they wanted to be able to vary the numbers of hours received from week to week: "Some weeks we need more support than is allotted." It was also a prob-

lem that respite services had restrictions in the kinds of tasks performed and in portability of services: "Currently I have respite workers who cannot give medications or take my son in the car. If my son is in a facility and needs extra support I cannot send a respite worker." They were also concerned with the quality of respite services, claiming that the availability of skilled care was limited, there was a lack of back-up staff and a high turnover rate of staff. One woman reported: "Our family has had 15 changes in staff in the last 2.5 years."

Health and Social Services

The majority of parents used generic and specialized health and social services.

All of the respondents reported that their children used health or social services specifically related to their disability. Most used a pediatrician (almost 60%) and also accessed the services of a family physician (70%). The majority used specialized services such as neurologists (87%), physical therapists (70%) and behaviour therapists (54%).

Some health and therapeutic services were difficult to access.

However, many mothers found that some services were difficult to access. The hardest to access were therapies: speech, occupational, recreational and physical. Many parents reported that therapies were delivered primarily through the education system. However, they criticized the way these supports were provided, finding them sporadic, time limited, and consequently of little value. They were further frustrated by the fact that these supports were tied to the education system, and could not be accessed at home. One parent stated: "Physical therapy will not come to the house, only the school. So there is no physical therapy if my child breaks a leg, or after surgery."

Some felt frustrated because their child was not eligible for therapies available through the schools, though they needed them. To some, these decisions felt arbitrary: "There is simply a lack of interest in working with my son." Others blamed lack of access on inappropriate eligibility criteria: "Speech [therapy] ... was actually denied because it was assessed that she did not have enough pre-speech." Others said access was determined by type of impairment because "there are strict divisions between education and health ... children with developmental disabilities do not get speech, occupational therapy or physio."

Parents whose children attended school in systems that did not offer these services were equally frustrated, though this scenario was infrequently reported. One woman complained that physical and occupational therapy were not available through her child's schools, and the only available services were two hours away.

Some felt that problems arose when they dealt with a high turnover of professionals because they could not develop good ongoing relationships. Others suggested that there were just not many good professionals to choose from. One respondent voiced her concerns regarding medical specialists and an inability to "shop around" for a good fit: "There are not many specialists to choose from, if you do not care for one."

Health care cutbacks were thought to be the reason for difficulties parents experienced in accessing health care services. In general, they found specialized medical and therapeutic services already difficult to access, and indicated that the situation is getting worse. One parent reported: "Speech, occupational therapy and physical therapy have been severely limited or completely done away with because of cutbacks."

Parents were generally satisfied with the health and therapy services they received.

Quite a few parents reported satisfaction with the health and therapy services when they received them. Over 75% tended to be satisfied with pediatricians, family physicians, medical specialists and behaviour therapists, while over half were satisfied with their physical therapists. Some professionals were praised for their understanding and responsiveness to families' needs.

Medical professionals lacked knowledge about disability, inclusion and family concerns.

Yet many parents also pointed to difficulties they had in dealing with such professionals. Parental dissatisfaction with pediatricians was largely based on doctors' lack of knowledge about disabilities: "He has a limited knowledge of autism and I constantly have to intervene in hospital care." Regarding the lack of awareness about disability issues, some noted: "They seem more interested in tests and diagnoses than with the whole child."

Specialists were also found to be insensitive, overly focused on testing and reluctant to listen to parents' needs and concerns: "There was a great lack of understanding of what parents are going through on a daily basis, including the emotional drain. The way information was presented by these professionals did not help." In cases where doctors provide generic services, some mothers felt they displayed a surprising lack of knowledge about different types of disability. They also demonstrated limited awareness of the social aspects of disability. Parents felt such professionals need broader and more community-based information.

Health professionals were sometimes insensitive, unresponsive and blaming.

Health professionals were also criticized for being unresponsive ("some of the professionals said my child would never walk or talk so what was the point in doing any special testing"), and for not providing sufficient information ("from birth I received no information about my child's disability"). Some parents described situations where professionals blamed them for their child's disability ("I was attacked after the birth of my child: 'What did you do? Fall? Drink? Paint?'").

Some doctors were also criticized for being insensitive, sometimes to an extreme, as in the following situation:

> *"One time I was in a doctor's office and there was a medical student there as well and the doctor said, 'This is the child who will probably be dead in a year.' Until that moment, we had never been told anything about her disability/illness being fatal. It was inexcusable."*

Income Support

Quite a few families were living in poverty.

While some families were quite well off (nearly 30% reported annual employment earnings of over $50,000) many others were quite poor. Approximately 38% reported employment earnings of less than $30,000 a year, and more than half of these made less than $20,000. Regardless of parents' annual income, the out-of-pocket costs spent on children with disabilities were considered to be too high.

Most parents needed increased financial support.

A majority of the women indicated that increased financial support is crucial to their ability to support both their children and themselves, especially when considering the extra stress that financial worry has on them. Some felt they should be entitled to increased financial support, since they recognized that their unpaid caregiving was replacing formerly paid work. One woman stated: "I am currently providing constant care and saving the government an incredible amount of money. Some remuneration would be of great assistance."

General Support Issues

Families experienced differential access to supports according to geographical location.

It is clear that families face many struggles in accessing the quantity and quality of supports they need. A number of factors seem to have an affect on access to supports. One is geographical location. Families experience differential access depending on the province and region in which they live. One family, moving from one province to another, was shocked to discover that the level of support or commitment to inclusion that had been formerly experienced was reduced.

People in rural areas also tend to be disadvantaged in terms of service access. One parent in the study had moved from rural to urban areas for the sole purpose of accessing services. The rural location "had a complete lack of support and information resources." Furthermore, not only do they have less access to transportation services, rural families tend to have to travel greater distances to get what they need.

Professional attitude resulted in differential access.

Another factor common to various support services was the impact of individuals and professional teams' attitudes on access to support for families. Whether in the education system, child care, homecare or health care services, when administrators and staff had a positive attitude toward children with disabilities and their families, and supported inclusion in the community, parent satisfaction rose. In fact, many mothers spoke of the difference that even one professional who supported them would make in their lives.

Eligibility criteria for supports was inappropriate and restrictive.

Another common feature of service delivery systems that restrict access is strict, inappropriate and medicalized eligibility criteria. As one mother reported with respect to respite care: "The criterion for needs assessment is ridiculous."

Funding cuts are affecting parents' access to supports.

Funding cuts are having drastic effects on parents' access to supports in all sectors: "You cannot turn around these days without another support being taken away, limited in some way, or having user fees applied." Parents are worried about what this will mean for themselves and are fearful about what the implications may be for their children throughout their lives. One mother expressed this fear: "I have to plan for the entire life of my children with what appears to be fewer and fewer supports .... I live with incredible fear for them, who else do they have but me?"

Parents need access to supports, and these issues urgently need to be addressed. One mother put it simply: "I want them to have a life. They need opportunities to develop.

This is not possible for me to do without needed supports and services."

Community Inclusion of Children

Children were included in communities to varying degrees.

Mothers reported that their children were included in communities to varying degrees. A majority (over 65%) of children with disabilities in this study had friends outside the home, spending on average three-and-a-half hours a week with them. Most mothers (80%) felt that their children had some opportunity to be involved in social and recreational activities, but felt these opportunities were limited. A few mothers felt their children were quite isolated in this regard. Many mothers wanted to see recreation and leisure supports and services made more available or expanded.

Access to support leads to community inclusion.

Children's inclusion in communities seems to be correlated, in part, with the supports they are receiving. Among the mothers who say they are satisfied with supports, over 90% say their children have friends outside the home. Of those who are not satisfied, only 58% say their children have friends. When children access the quantity and quality of supports they need, they are more likely to be involved in activities with other children in the community. Similarly, those who have access to inclusive education, and go to school with their neighbourhood peers are significantly more likely to have friends (74% who attend regular classes compared with 50% who attend segregated classes).

Children with speech and mental health disabilities experience the greatest barriers.

Type of disability also seems to have an impact on whether or not children are included with other children in the community. In particular, those who experience difficulties with speech seem to have a hard time making friends. Every child who reportedly did not have speech difficulties had friends, according to their mothers. Of those who did have speech problems, only 57% had friends. Similarly, children with mental health disabilities were less likely to have friends (41% with mental health disabilities, compared to 79% without).

Children participated in both segregated and inclusive recreational activities.

Children were involved in a wide range of recreational activities. Some of these were specialized programs for children with disabilities, such as the Special Olympics, other "wheelchair sports," segregated summer camps or day camps, and therapeutic horseback riding. Children also participated in a wide range of inclusive community activities, like bowling, swimming, soccer, music or dance lessons, groups like Beavers or Girl Guides, karate, gymnastics, "teen hang-outs" at youth centres and library story time.

Parents experience barriers to accessing both segregated and inclusive recreational activities. Some, especially those in rural areas, cited distance from activities as a problem. Some programs were too expensive for many families to access. In other cases, recreational programs were unable (for lack of resources) or unwilling to include and accommodate a child with a disability.

Communities differed in their attitudes toward children with disabilities.

Responses were also mixed with respect to community attitudes towards children with disabilities. Communities differed in the degree to which they were positive and willing to include children with disabilities. Approximately half of the mothers believed their children were valued and respected in their community only "somewhat" or "a little." In fact some parents experienced quite negative community attitudes: "The community is terrified of these kids. We need a true commitment to inclusion, making the community more responsible by someone other than the parent." The other half felt that their child was valued "quite a bit" or "a great deal." While some differences in attitude may be attributed to differing responses to children with different types of disabilities, attitudes do appear to be consistent between communities even for the same child. One parent had moved from one community to another, and was astounded at the difference in attitude: "After we moved we found a huge difference between communities regarding understanding, acceptance and accessibility." Heartened by this change, they recommended that resources be directed toward community education and awareness.

Mothers were passionate in the message they want to send to their communities about their children. One mother recommended:

> *"Get to know him ... he is a member of the community ... he needs supports to utilize his talents to be a contributing member of the community. Any money spent on him is an investment in the community."*

V.
EMERGING THEMES AND POLICY DIRECTIONS

A number of overarching themes emerge from the findings of this study. The research findings support a large and growing body of literature that calls for urgent policy action in the area of supports for children with disabilities and their families. Much is applicable to the situations of families and others supporting adults with disabilities and seniors as well, and some is broadly applicable to the concerns of families, and in particular, female caregivers. The following themes point to future directions for policy:

- Parents, particularly mothers, spend an incredible amount of time caring for and supporting their children. On average, they spend 50 to 60 hours per week on personal care, advocacy, coordination of services and transportation directly related to their child's disability. This includes an average of 14 hours per week in advocacy and coordination related to their child's education. All of this time is in addition to time they put into general domestic responsibilities and paid work. In order to do so, they have taken on a number of roles that greatly increase their responsibilities, impact on their physical, emotional and social status, and in some cases these external roles actually impede or undermine effective parenting.
- Parents face an ongoing need for respite services because of the demands of caring for a child with a disability. Not only do they need more hours of service, they also need a wider range of respite options to choose from. They need services characterized by flexibility in terms of how much and when hours are allotted, and portability of service.
- Parents also need greater access to affordable accessible day care and after-school care inclusive education and therapies such as speech, occupational, behaviour management and physiotherapy. Cutbacks to such services in schools, restrictive eligibility criteria and lack of portability of services have created significant inequities in access to services considered essential for healthy child development in this group.
- Parents need access to financial support and funding to help cover the costs of aids and devices and home accommodations.
- To ensure flexibility, portability and parent and child choice in service delivery, funds need to be attached to the individual instead of/or as well as the delivery agency.
- Parents need access to education and training at home concerning how to support their child with regard to specific types of tasks (i.e., personal care, therapy, service coordination, advocacy, assessment of need for technical or home accommodation).
- Women need access to supports to participate in the paid labor force if they choose — including both community supports for their children and a supportive employment environment.
- Unpaid caregiving, primarily by women, is replacing paid work formerly performed

by paid professionals. Because it is unpaid this work tends to be invisible to the politicians and policy makers and is not recognized as skilled labour. Women are not only unpaid, they have no access to vacation or sickness benefits, retirement pensions, occupational health and safety benefits, and their own career opportunities are compromised. Unpaid work needs to be characterized as work and compensated in some way.

- Service providers, such as in-home respite workers, have limited training and qualifications, and tend to have high turnover rates. Parents indicate these issues compromise the service they receive. There is a need to explore options for support worker training, as well as the factors resulting in high rates of staff turnovers.
- Education, child care and leisure/recreation professionals also need access to information about disability issues and inclusion. Funding for professional development needs to be built into programs and systems. Similarly, health professionals and therapists need further training and access to information regarding specific disability types, social aspects of disability, parental concerns and community inclusion.
- The experiences of children and families are affected by the degree of community responsiveness to support needs and inclusion in their communities. Investment is needed in community capacity to support children, through directing resources to both generic and specialized organizations and agencies that provide services to children and families.
- Commitment to inclusion and levels of supports and services available is inconsistent across provinces and municipalities. A national framework needs to be developed that would ensure families across the country could expect to receive the support they need. This study found that inclusionary policies in education and community services are important to the extent that a child can make friends and participate in social and community activities — all key ingredients for healthy child development.

The key themes that emerged in this study concur with other recent studies examining public policy and family caregiving. For example, a recent study of home care policy for families providing supports to aging family members (Anderson & Parent, 1999) lays out a number of key policy directions. These include, among others, directives to establish a policy council on home care to develop a vision and principles for home care in Canada and a Task Force on Human Resources to develop policies and recommendations for improving homecare delivery. The report also recommends that supports be provided for informal caregivers in the home and workplace, and that such work be recognized through remuneration in the form of employment insurance for home care leave, tax credits and respite care. Further recommendations included supporting volunteer-based organizations, increasing corporate responsibility, supporting the development of information technology (databases on homecare), development of supportive housing models and commitment and investment in research on home care.

The issues faced by families supporting elderly members are clearly similar to issues faced by parents caring for children with disabilities. The support needs, and the policy solutions for both groups overlap. Policy measures are required which address the needs of both groups in the context of a comprehensive and inclusive policy framework for supporting families in Canada

VI. CONCLUSION

Children with disabilities are more and more likely to live with their families for most of their childhood. This trend benefits children and families in may ways. Mothers point to the positive impacts that arise from caring for their children, describing the ways they have grown, and say they have become stronger, learned skills, and tended to look at life in new ways. However, the stress caused by lack of supports has had impacts on families that need to be addressed by social policy. Mothers, in particular are affected, as they tend to be the primary caregivers of their children. This study revealed that they spend considerable time in the caregiving role, in addition to other domestic and work responsibilities, engaging in a diverse range of activities. They receive limited support from their spouses, extended family and friends, relying primarily on paid supports and support groups. In general, they do not receive sufficient support. This lack of support has negative impacts on their own health and well-being, and that of their whole family.

A major impact on mothers is restriction in their paid labor force participation. Though many of the women in this study wanted to be working, they were restricted from doing so by child care responsibilities, lack of support, and barriers in the workplace. Some felt that since they were already working full time as primary caregiver, their unpaid contributions deserved recognition.

Mothers' health and well-being were also compromised by their workload. They reported high levels of physical and emotional stress, and looked to support from friends, medications, and counseling to deal with it. Their clear indication that stress was caused by lack of support, not their child, underscores the urgent need for policy to address these issues.

Families need a number of different community supports and services. Their satisfaction with these services varies. They reported difficulties accessing inclusive education, day care, transportation, respite services, therapy and income support. Families in urban areas, and in certain provinces, reported greater access. Access was also dependent on the attitudes of professionals, and restricted by inappropriate, stringent eligibility criteria and government funding cuts. As a result mothers spent considerable energy fighting to get what they needed, and often ended up frustrated and their needs unmet. They called for flexible, portable services that would respond to the unique and changing needs of their families. They found that the attitudes of professionals made a difference. They lauded those who had information about disability and supported inclusion, and criticized those who were insensitive, unresponsive, and uninformed. They recommended not only increased resources and funding in these areas, but also professional development to improve service provider attitudes.

Children were included in communities to varying degrees. This depended in part on their access to supports and inclusive programs, on their type of disability, and on community attitudes. They participated in both segregated and inclusive recreational activities, though they met a range of barriers to access, such as difficulties with transportation, affordability and willingness and capacity to include them. Their parents recommended inclusion training for com-

munity workers, more resources and community education to address barriers to inclusion.

This report concludes with a set of future directions for policy based on these findings. It seems clear that integrated, individualized, responsive services and supports have a major impact on child and family well-being. It is critical that a holistic approach be taken in the development of supports and services. Recreation, leisure and social programs are of little value to a growing number of Canadian families if child and family accessibility needs are not considered. Transportation, physical access, educated staff and financial resources of families must be part and parcel of the design of each program. It may seem daunting to consider education, recreation, home care and family support programs in this light. However, without more focused attention on the needs of children with disabilities, their primary caregivers, and their families more generally, the social isolation, burnout and economic disadvantage of these families will persist. As mothers in this study so eloquently stated, the long-term cost will be twofold: the restricted potential development and contribution of their children and the social and economic costs of mothers and families asked to go beyond the limit.

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